# Traumatic Brain Injury Advisory Council

# Meeting of January 26, 2001

## Minutes

The Traumatic Brain Injury Advisory Council met in Conference Room M-653 in the Moreton Building at the Texas Department of Health at 1100 West 49<sup>th</sup> Street, Austin, Texas.

#### MEMBERS PRESENT:

Mary Adams, Cheryl Amoruso, Ken Archer, Kate Burgess, Mary Carlile, Nancy Childs, Pat Craig, Julia Hannay, Addie Horn, Walter High, Jeff Latham, Carrie Morris, Susan Penfield, Roger Webb, Cathy Rich, Jesse Seawell, Larry Swift, Les Young

# MEMBERS NOT PRESENT:

Kim Arlinghaus, Carol Gage

#### TDH STAFF PRESENT:

Linda Jones, Kathy Reeves, Tammy Sajak, Sheila Tucker, Lesa Walker, David Zane

# WELCOME AND INTRODUCTIONS:

Carrie Morris, Chair, called the meeting to order at 10:00 am. Following introductions, Lesa Walker announced that Council member Larry Swift had been hired as the TBI Project Director, and that interviews for the TBI Coordinator positions were being set up.

#### PUBLIC COMMENT:

None.

#### **REVIEW OF MINUTES:**

No changes were suggested. The minutes of the 10/27/00 Council meeting were approved as presented.

## OVERVIEW AND HISTORY OF THE TBI GRANT:

Susan Penfield provided the members a brief summary of the development of the TBI project and its goals of identifying people with TBI and reducing barriers to services available, and increasing the services available. She said the hiring of Larry Swift as Project Director was an important step as his expertise will provide better focus for the project.

In the discussion that followed, points were raised about the importance of making current resources work better for the TBI population, especially in minority communities. Julia Hannay noted that about 75% of minority persons with TBI do not get rehab after they leave the hospital. It was suggested that the reasons members of some cultural groups are not using available services need to be explored and addressed.

Jesse Seawell said that this Council needs minority members. There was general agreement and a question regarding how the members of the Council are appointed. It was clarified that Council members are appointed by the Health and Human Services Commissioner. It was agreed that nominations be sent to Sheila Tucker (prior to Feb. 12) and to Larry Swift after that date.

It was noted that Texas and Mississippi are the only states with no rehab coverage under Medicaid.

#### COMMITTEE MEMBERSHIP AND ACTIVITIES:

Carrie Morris invited members to review the current workgroups and determine if others were needed, i.e. a minority outreach group. After some discussion of what would be a practical number of groups and what issues need to be addressed, a motion was made to reduce the number of groups to three standing committees: 1) Identifying people with TBI, 2) Removing barriers, and 3) Disseminating information. The motion carried. A sign-up sheet was distributed. (The current groups and members are attached.)

#### BIATX PROPOSAL TO CONTRACT OUTREACH/EDUCATION

Rachel O' Connor, Regional Director with the National Brain Injury Association, and James Misko, Education Committee Chair with the Brain Injury Association of Texas, formally presented the BIATx proposal to contract with the TBI Project (TDH) for achieving the education and outreach goals of the project.

James Misko stressed that many of the goals of the state organization and the TBI Project are the same. Working collaboratively rather than duplicating work will enable everyone to accomplish more. He said that the BIA in TX already has a list of 1200 families interested in receiving materials. The BIA is actively working on reaching existing support groups. Most of the BIA materials are available in Spanish as well as English. They are written at a 7<sup>th</sup> grade reading level and aim to provide information about rehabilitation. Some Council members thought that a lower reading level was advisable. Also, there was some concerns raised about reaching other populations in their language, such as the large Vietnamese community in Texas.

Misko and O'Connor said that the national BIA was very interested in supporting the work in Texas and wanted to make a contribution to the education/outreach in Texas. The national BIA will assist the BIATx organization in obtaining computers, software, and other equipment. The national organization will provide intensive advocacy training in Texas to help create a cohesive group of leaders and advocates in Texas. They pointed out that other states involved in the TBI State Demonstration grants also contract with their state Brain Injury Associations.

Council members raised some questions regarding the details of the amount requested and accountability. After a lengthy discussion, the Council agreed that the project director should handle those concerns. A motion was made to support the BIATx proposal, with the understanding that the project director, Larry Swift, will be responsible for developing the scope of work and the contract and will keep the Council leadership informed of progress. The motion carried.

# MOU BETWEEN TDH AND THE TBI ADVISORY COUNCIL & UPDATE ON TBI REPORTING RULES:

David Zane of the Injury Epidemiology and Surveillance program at TDH presented a draft MOU that describes the purpose, background, and period of agreement. The Health & Safety Code stipulates that TDH and this Council must enter into an MOU to exchange relevant injury data on an ongoing basis, maintain confidentiality of that data, allow the Council to review and comment on reporting rules, and cooperate in investigations regarding TBI. The proposed agreement indicates that TDH will provide the Council aggregate TBI statistics, specifically the number of TBI cases received by the Trauma Registry during the most recent quarter, annual analysis of this data combined with death certificate information, and any other special reports pertaining to TBI.

Council members asked David Zane about the comments made regarding the proposed rules reviewed by the Council in October 2000. He said he was not recommending any of the changes suggested by the Council. The reasons were confidentiality issues and feasibility of requiring the changes in reporting from hospitals. After discussion of these issues, the Council by unanimous vote, asked the Chair and other Council members to present the Council's views and recommendations to the Board of Health at it next meeting on February 23, 2001, when the rules will be voted on.

#### TBI GRANT APPLICATION & REVISED WORKPLAN/BUDGET

Lesa Walker reported that TDH is submitting a continuation application for the TBI grant by the February 8 deadline; a revision of the workplan and budget will need to be completed by March. She asked for the Council's guidance on what changes should be made. Council members asked about the original objectives, saying that there was no input from the Council at that time. There was also a question regarding the difference between the Trauma Registry and the TBI database referred to in the grant workplan. After discussion, the Council determined that members needed more time to consider the details of the workplan. It was agreed that comments/suggestions regarding the workplan and budget would be e-mailed to Sheila Tucker.

# PROMOTING INDEPENDENCE COMMITTEE FINAL REPORT:

Larry Swift noted that although the committee did adopt some of the recommendations forwarded by the TBI Advisory Council, there is little specific mention of TBI as the committee did not want to single out specific diagnoses or conditions.

Next meeting:	April 20, 2001.
Carrie Morris,	Chair